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Parental decision-making during the cochlear implant selection process

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**PARENTAL DECISION-MAKING DURING THE COCHLEAR
IMPLANT SELECTION PROCESS**

by

Melissa Stewart

**An Independent Study submitted in partial fulfillment of the requirements for
the degree of:**

Masters of Science in Deaf Education

**Washington University School of Medicine
Program in Audiology and Communication Sciences**

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Approved by:

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***Abstract: The focus of this study was to examine the decision-making process
parents experience when choosing a cochlear implant for their child and create
a parent-friendly, comprehensive comparison chart of current cochlear implant
technology for parents to use in the future.***

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Introduction

Parents often are devastated when their child is diagnosed with a disability or disorder. They do not plan for anything except raising a typically-developing child. These types of diagnoses can include, but are not limited to; genetic, physical, cognitive, or psychological disorders. Parents of children with disabilities feel grief over the fact that their child is not who they expected, and guilt that they may have caused this disability (Chute & Nevins, 2002; Luterman, 2008). A disability may not be identifiable when the child is born, and in other cases the disability is obvious at birth. For those who are not diagnosed at birth, the time delay in discovering a disability can compound guilt, as parents wonder why they did not notice sooner and think about what they could have done for their child. Parents' initial reactions will be influenced by many factors, including personal beliefs, knowledge of the diagnosed disability, and interactions with health professionals (Duncan, 2009; Li, Bain, & Steinberg, 2003; Li, Bain, & Steinberg, 2004). Even a physician's individual opinions and attitude may affect the way parents perceive their child's diagnosis (Li et al., 2004). All of these emotions combined affect the decisions this child's parents must make in the near future and later in the child's life.

Parents of children with disabilities must make decisions about possible treatment or care available to their child (Duncan, 2009). This might be something major, such as surgery or routine hospital visits, or something less drastic, such as medication or therapy. Additionally, the disability and associated methods of treatment or care may be foreign to the parents, which makes decisions about treatment seem vast and unknown (Hyde, Punch, & Komesaroff, 2010). For parents, coming to a decision about something they know little about can be stressful and confusing (Duncan, 2009; Hyde et al., 2010; Incesulu, Vural, & Erkam, 2003). Making effective

decisions requires confidence (Duncan 2009). In order to feel confident in their decision-making, parents must acquire information from a variety of sources and consider all possible outcomes (Incesulu et al., 2003).

It is no doubt stressful for parents to make decisions regarding their children, especially those that have an effect on the child's health and development (Duncan, 2009; Hyde et al., 2010; Incesulu et al., 2003). On top of this stress, some of these decisions have time constraints, which can make an already stressful decision seem more extreme (Chute & Nevins, 2002); Duncan, 2009; Li et al., 2003). A looming deadline brought on by urging from a physician or the need to start treatment quickly can make parents feel as though their decision is being rushed (Hyde et al., 2010). Other times, parents may have several options of services for their child, or several decisions to make for their child, causing them to feel overwhelmed by choices and responsibility (Duncan, 2009). In any situation, a decision that will affect the child for the rest of his or her life puts pressure on the parents to choose "correctly," though this perfect choice is often undefined and may be nonexistent (Chute & Nevins, 2002). Parents may feel premature regret over making the wrong decision, or they may anticipate resentment from the child if they choose something with which the child may not agree later in his life (Incesulu et al., 2003). Furthermore, physicians cannot always guarantee treatments will yield a specific outcome. This in and of itself can cause anxiety, as well as the realization that the outcome may not match the expectations of the parents (Chute & Nevins, 2002; Duncan, 2009; Hyde et al., 2010).

Time and stress have great influence on the decisions parents make for their children, but other factors such as their personal beliefs and values, their understanding of the information presented to them, and their emotional state can influence the decision-making process (Duncan, 2009; Li et al., 2003; Li et al., 2004). There are also financial implications related to treatment

decisions. Health insurance may cover the cost of some treatments and technologies, but the costs left to the parents may be more than anticipated, causing more stress (Chute & Nevins, 2002; Kluwin & Stewart, 2000; Li et al., 2004).

The decision-making process parents experience varies from case to case and from diagnosis to diagnosis. Parents of children with a diagnosed hearing loss face several decisions regarding communication method and assistive listening technology, among other issues (Chute & Nevins, 2002; Li et al., 2003). One particular decision-making process about which little is known is the process of deciding which cochlear implant the child will receive, should the parents choose to have their child implanted. This independent study will take a deeper look at how parents make this decision and which resources they use to help them decide.

When the disability of the child is hearing loss, one of the first decisions parents must make is how they want their child to communicate (Chute & Nevins, 2002; Li et al., 2003). There are two main forms of communication for an individual with hearing loss: manual communication (American Sign Language, Signed Exact English, etc.) and spoken language (Li et al., 2003). (There are instances when both manual communication and spoken language are used in a combined approach, but for the purposes of this paper, these methods will not be discussed.) There is widespread disagreement about which method children with hearing loss should use, but ultimately the goal is to provide the child with a form of communication (Li et al., 2003). The former requires parents to learn how to sign in order to communicate with their child. The latter requires parents to seek help to determine which technology will aid their child in hearing spoken language so that he or she may learn how to listen and talk (Chute & Nevins, 2002). Because more than ninety percent of children with hearing loss are born to parents with typical hearing, this decision has the added stress of considering what is “normal” for the family,

and knowing that their choice may not align with what others believe is the “right” decision (Vaccari & Marschark, 1997; Li et al., 2003). Outsider opinions can impact how parents perceive their own beliefs and ultimately affect the decision that is made regarding communication modality (Chute & Nevins, 2002; Hyde et al., 2010). Whether the parents choose manual communication or spoken language, it is critical that the communication modality is chosen sooner rather than later so language acquisition can begin as soon as possible and valuable time used to learn language not lost (Chute & Nevins, 2002). Research shows there is a critical period for the acquisition of language, and prolonging the decision of communication modality could make learning language more difficult, and may result in a language delay for the child (Hayes, Geers, Treiman, & Moog, 2009; Nicholas & Geers, 2007).

Hearing aids and cochlear implants are the two most common assistive listening technologies for children who have hearing loss. Audiologic testing must be completed to establish both the severity and type of hearing loss the child has, and to determine which hearing device or devices will be most appropriate for the child (Chute & Nevins, 2002). The United States Food and Drug Administration (FDA) regulations state that in order to receive a cochlear implant, a person must be at least two years old and have a severe to profound sensorineural hearing loss bilaterally, or twelve to twenty-four months old with a profound sensorineural hearing loss bilaterally, and demonstrate limited benefit from binaural amplification with hearing aids (United Healthcare, 2013). The FDA does not currently approve of implantation of children under twelve months of age. The only exception to these regulations is children who have had meningitis. These children can be implanted immediately regardless of age because there is a risk of cochlear ossification after meningitis. However, surgeons frequently implant children younger than twelve months of age given that the FDA candidacy criteria are not binding.

It is important to discuss how a cochlear implant works so that the decision-making process can be fully understood. A cochlear implant is a device that has two main parts, one internal portion and one external portion. The external portion of the device includes a speech processor, a microphone, a battery or battery rack, a cable, and a coil. The microphone collects sound, which the external processor then converts into digital information. This information is sent up the cable to the coil which transmits the information across the skin to the internal portion of the device. The internal portion of the device is comprised of a receiver/simulator and an electrode array. The receiver/stimulator converts the digital information into electrical signals and sends them to the electrode array which is situated inside the cochlea. The electrical signals stimulate the auditory nerve and the information travels up the auditory pathway to the brain, where the sound is perceived. The cochlear implant works by retrieving sound and delivering it directly to the auditory nerve, bypassing the damaged hair cells of the cochlea that cause the hearing loss (Chute & Nevins, 2002; Cochlear Ltd., 2014). Some cochlear implants are configured so that the user can wear the external processor behind the ear and some are designed so the processor and/or battery is worn on the body. The behind-the-ear version employs an ear hook and sits on the ear similar to a hearing aid. The body-worn version uses a clip or an arm band to hold the processor on or under the user's clothing. In either configuration, the external coil rests on the head directly over the internal receiver and is held in place by a magnet.

The most reported reason parents choose cochlear implantation for their child is the desire for their child to communicate with the majority of the population by listening and talking (Chute & Nevins, 2002; Hyde et al., 2010; Kluwin & Stewart, 2000; Li et al., 2003; Li et al., 2004). Parents who decide they want their child to be considered for cochlear implantation face added stress and time pressure. The implantation surgery is invasive and carries risks (Chute &

Nevins, 2002). Moreover, the stress of surgery usually comes on the heels of the initial diagnosis, which amplifies the stress. Likewise, the current push in auditory-oral deaf education for implantation to occur younger and younger supports the understanding that earlier implantation can lead to more successful and more rapidly-progressing outcomes in speech, language, and auditory skills (Hayes et al., 2009; Hyde et al., 2010; Nicholas & Geers, 2007). This can cause parents even more worry as they navigate the short period of time before their child has missed the window of opportunity for spoken language acquisition (Hyde et al., 2010).

When parents decide they want a cochlear implant for their child, and criteria for candidacy have been met, a decision must be made regarding which cochlear implant their child will receive (Incesulu et al., 2003). Information about cochlear implants can be obtained from many different resources. Cochlear implant manufacturers provide information about their respective devices, audiologists and implant centers may provide information about all three cochlear implant manufacturers' devices, parents of children who already use cochlear implants have experiential information regarding the implantation process and the devices themselves, and the internet has a plethora of information about cochlear implants and hearing loss in general. Despite this abundance of resources, information provided may be biased, conflicting, and/or confusing to parents (Incesulu et al., 2003).

Parents may obtain potentially subjective information from cochlear implant manufacturers (Chute & Nevins, 2002; Clamp, Rotchell, Maddocks, & Robinson, 2013). Since every cochlear implant manufacturer is a business, one of their main goals is to sell their particular cochlear implant. They want to make their device seem like the best cochlear implant on the market. This means that the information they provide could be skewed or biased. In addition, they may pick one main selling point that is not directly addressed by the other two

cochlear implant manufacturers, which may leave parents wondering how the devices compare in that specific respect. For instance, if one cochlear implant manufacturer boasts their device has the longest battery life, the second focuses on their device's superior programming abilities, and the third claims their device has the most beneficial number of electrodes, it will be difficult for a parent with minimal knowledge of cochlear implants to objectively compare the three devices.

The bias doesn't always end with manufacturers. Sometimes audiologists and implant centers prefer one brand of cochlear implant (Chute & Nevins, 2002; Hyde et al., 2010; Kluwin & Stewart, 2000; Li et al., 2004). Additionally, some surgeons will only implant one brand of device (Chute & Nevins, 2002; Hyde et al., 2010). Information received from these sources may be prejudiced, and can change how parents think of one cochlear implant or another (Chute & Nevins, 2002; Clamp et al., 2013; Hyde et al., 2010; Li et al., 2004).

Parents of children who already use cochlear implants will know the most about their child's particular device (Hyde et al., 2010). This means they will know how the device functions in real-world situations, which features are beneficial and which ones may not be used as frequently, and what types of problems might arise after implantation and activation. Parents can be a resource for much of the implantation process and what happens afterward, but their knowledge of the cochlear implants themselves may be limited to the brand of device their child has.

There is very little research that examines the decision-making process of parents choosing which cochlear implant their child will receive (Kluwin & Stewart, 2000). Of the three cochlear implant manufacturers' devices sold in the United States, sometimes the parents choose, sometimes the audiologist makes a recommendation, and sometimes it is the surgeon's preference (Chute & Nevins, 2002; Clamp et al., 2013; Incesulu et al., 2003). This decision could

be made more easily if parents could compare each of the three cochlear implant manufacturers' devices side by side. However, there is no such comprehensive, easily understood tool that affords parents this opportunity (Hyde et al., 2010). Presently, there are two charts that provide comparative information about current cochlear implants; however, neither uses parent-friendly language, nor are they easily understood by individuals who do not have extensive background knowledge about cochlear implant technologies. This independent study examined how parents of current cochlear implant users decided which cochlear implant their child would receive. Survey data collected from parents then was used to create a parent-friendly, comprehensive comparison chart of the cochlear implants currently available in the United States from the three cochlear implant manufacturers.

Methods

Participants

In order to obtain experiential information regarding the decision-making process parents go through when choosing a cochlear implant for their child, parents were surveyed about their respective experiences. Forty-two OPTION Schools across the United States of America were contacted by phone and email to request that they distribute parent recruitment letters to enlist participants for research. Twelve of these schools gave permission for their parents to receive a prepared recruitment letter. The letter was disseminated by the schools to their students' parents via email or hard copy, depending on each school's preference. Participating schools were asked to give the recruitment letter to parents of all students currently in attendance, regardless of device use, age of the child, or other factors. Participant inclusion/exclusion criteria were addressed within the parent recruitment letter, where participant qualifications were stated, and

were further accounted for in *Question One* of the survey, where parents were asked to list the month and year of their child's first cochlear implant.

Materials

Within the recruitment letter, parents were asked to participate in an online survey about their experiences when choosing cochlear implants for their children. None of the survey questions asked parents to provide any identifying information. Thus, the survey was completely voluntary and anonymous. The total number of surveys distributed to parents is unknown (as to preserve anonymity of the parent groups), but seventy surveys were completed before the survey was closed in December 2013. Of these completed surveys, fifty were useable for the purposes of the study. A total of twenty surveys were not included in the results of the study for various reasons. Two of these surveys were excluded because they did not meet two of the inclusion criteria, whereas the other eighteen were excluded because they did not meet one of the inclusion criteria.

The first group of survey exclusions included parents of children who were implanted before January 1, 2006. In the parent recruitment letter, it was stated that eligible participants were parents of children currently using at least one cochlear implant received on or after this date. This cutoff date was chosen to limit survey respondents to parents of children who have received more recent cochlear implant technology, within the same generation of technology from each cochlear implant manufacturer. *Question One* of the survey asked parents to list the month and year of their child's first implantation. Six surveys that were completed by parents who listed an implantation date before the cutoff date were not included in the results. Additionally, two surveys completed by parents who did not list an implantation date, and one

survey completed by a parent who listed only the month were not included in the results. This information accounts for nine of the twenty surveys that were not included in the results of the study.

Because one of the aims of the research was to gather experiential information from parents who actually were given the opportunity to decide which cochlear implant their child would receive, surveys that were completed by parents who did not choose their child's cochlear implant manufacturer were not included. *Question Three* of the survey was designed to exclude any parents who responded that they did not have a choice of which cochlear implant their child received. Eleven surveys of parents who answered, "No, I did not have a choice," as well as two surveys of parents who skipped this question, were not included in the results. This information accounts for eleven of the twenty surveys that were not included in the results of the study.

The survey consisted of fifteen questions total. Five of the questions required parents to choose one answer (multiple choice), three of the questions allowed parents to choose more than one answer (unlimited choice), and seven of the questions asked parents to provide information regarding their individual decision-making experiences or personal opinions about a provided cochlear implant comparison chart (free response). A link to the comparison chart was provided as an active hyperlink within the survey. This chart was created by Howard Samuels, one of seven contributors to an online forum called "cochlear implant HELP." This website and blog provide information regarding many topics related to cochlear implants and the implantation process. Permission was granted by Mr. Samuels to use his comparison chart as a reference within this study.

Survey questions addressed two large aims: how parents chose the cochlear implant their child received and what they thought about a cochlear implant comparison chart. These topics

included whether parents sought out or were given information regarding cochlear implants, from whom or from where parents received the information they were given, from whom or from where parents sought information about cochlear implants, in what format the information they used was presented, what was most important to parents when choosing a cochlear implant for their child, whether or not they thought having a cochlear implant comparison chart would have helped them in their decision-making process, which categories from the provided cochlear implant comparison chart they thought were beneficial, which categories from the cochlear implant comparison chart they thought were confusing, and what other categories they thought a useful cochlear implant comparison chart should include. For reference, a complete listing of the parent survey questions can be found in Appendix A.

Results

As stated previously, 50 of the 70 completed surveys were usable for this study. This means 71% of participants were parents who had a say in which cochlear implant their child received, and that their child's device was implanted on or after January 1, 2006. Only these 50 surveys are included in the following data.

The reported cochlear implantation dates ranged from April 2006 to November 2013, with the average date of implantation being July 2010. The cochlear implant manufacturers' devices were not equally represented. Specifically, 76% of parents reported that their child uses a Cochlear device, 20% reported their child uses an Advanced Bionics device, and 4 % reported that their child uses a MED-EL device. See Figure 1. Twenty-six parents, or 52%, stated they had a choice among all three cochlear implant manufacturers' devices when choosing a cochlear

implant for their child, while 24 parents, or 48%, reported they had a choice between only two cochlear implant manufacturers' devices. See Figure 2.

Parents were offered seven answer choices, including an "Other" option, in response to a survey question regarding their primary source of information when choosing their child's cochlear implant. The largest group, 58% of parents, reported their primary source of information was an audiologist. Additionally, 10% of parents considered the cochlear implant manufacturers to be their primary source of information, 8% reported theirs was a physician, 6% indicated theirs was friends or family whose children already had a cochlear implant, and 2% answered theirs was school(s). None of the parents who answered this question chose the answer that named friends or family who had limited knowledge of cochlear implants as their primary source of information. Finally, 14% of parents reported that their primary source of information regarding cochlear implants fell into the "Other" category. These seven answers included sources of information such as Developmental Therapist Hearing Services (DTH), the internet, a speech-language pathologist, an equipment support individual, surgeon or otolaryngologist (ENT), and a combination of audiologist and cochlear implant manufacturer information. One parent, or 2%, skipped this question. See Figure 3.

When asked to think about the information they used most when deciding which cochlear implant their child would receive, exactly 50% of parents reported they used information they had requested or looked for in as many places as they could. Furthermore, 32% of parents reported the information they used the most included some information they had requested or looked for themselves, and some information that had been given to them. Finally, 16% of parents reported they were given all the information they used most, and 2% of parents reported they requested or looked for information in only a few places. See Figure 4.

In regard to the information given to them without asking, parents could choose as many answers as applied when reporting from whom this information came. Most of the information, 88%, was reportedly given to parents by an audiologist. In addition, 32% of this information came from a physician, 16% of this information was provided by friends or family, 16% of this information came from school(s), and 12% of this information was given to parents by another source. These “Other” sources included therapists, early interventionists, other parents, and specific organizations. Since this was an unlimited choice question, the sum of the responses is greater than 100%. See Figure 5.

When reporting on information they requested or found on their own, parents could choose as many answers as were applicable when reporting from where or whom they received this information or where they found this information. Websites were used to find 70% of this information. Audiologists were asked for 64% of requested information. Cochlear implant manufacturers were asked for 46% of this information. Parents asked friends or family for 36% of this information. Physicians were asked for 24% of this information. Parents asked school(s) for 18% of this information. Finally, 12% of this information was requested from another source. Some of these “Other” sources were early interventionists or DTHs, other parents whose children use cochlear implants, auditory-verbal therapists (AVTs), ENTs, and specific organizations. Two parents, or 4%, skipped this question. Since this was an unlimited choice question, the sum of the responses is greater than 100%. See Figure 6.

Parents also reported on the format of the information they used. Parents could select all of the applicable formats of information they used during their decision-making process. Printed materials, such as brochures, flyers, or handouts, accounted for 86% of information used. Word of mouth from family, friends, and professionals, accounted for 84% of information used.

Electronic materials, such as cochlear implant manufacturer websites, online videos, or e-charts, accounted for 80% of information used. Since this was an unlimited choice question, the sum of the responses is greater than 100%. See Figure 7.

When asked what was most important when choosing a cochlear implant for their child, parents had to select one answer. Technological aspects such as the electrode array or speech processing strategy were the most important consideration for 38% of parents. A recommendation from an audiologist, physician, or other health professional was the most important consideration for 32% of parents. Performance features like battery life or water resistibility was the most important consideration for 16% of parents. The physical appearance of the device, including size and shape, was the most important consideration for 4% of parents. The cochlear implant's likeness to the devices of other children at their school or early intervention program was the most important consideration for 2% of parents. None of the parents chose pricing and insurance coverage as their most important consideration. In addition, none of the parents chose cochlear implant manufacturer support as their most important consideration. Furthermore, 8% of parents reported their most important consideration was not listed. Some of these "Other" considerations included FDA approval, preservation of the child's natural hearing, customer service of the cochlear implant manufacturers, and different combinations of the provided answer choices. See Figure 8.

Parents were asked to provide the "one thing" that helped them finally decide which cochlear implant their child would receive. The responses parents gave can be grouped into six categories. These categories are as follows: (1) reference from health professional, including audiologists, or FDA approval; (2) specific aspect of the device or technical specifications; (3) reliability and recall history of the device or opinion of the cochlear implant manufacturer(s) in

general; (4) familiarity with the device/cochlear implant manufacturer or popularity with other children; (5) the level of kid-friendliness provided by the device; (6) a “gut feeling.” Specifically, 34% of parents reported reasons that fell within category 2, 24% within category 3, 16% within category 1, 12% within category 4, 6% within category 5, and 2% within category 6. Two parents, or 4%, skipped this question.

Within the survey, parents were provided with a hyperlink that connected them to an existing cochlear implant comparison chart available from “cochlear implant HELP.” They were asked whether a chart like this one would have been helpful when deciding which cochlear implant their child would receive. A majority of parents, 78%, reported that a comparison chart would have been helpful when choosing their child’s cochlear implant, while 14% reported that it would not have been helpful. Four parents, or 8%, skipped this question. When asked to provide reasons why the chart might have been helpful, parents most commonly reported that it was easier to think about and compare the devices when they were presented side by side. Other reasons included the ability to view the devices without bias from the cochlear implant manufacturers, the level of detail provided, and the multitude of device aspects provided (both for comparison and to inspire questions to ask the audiologist). Two parents reported that they had attempted to create charts similar to the one provided. Parents who did not think the chart would have been helpful reported that the information was too detailed, too technical, and not easy to understand. One parent specifically reported that the chart needed more parent-friendly explanations.

When asked to list the five most beneficial categories on the existing chart, parents reported the following: (1) information about the electrodes and electrode array (e.g., number of electrodes, length of array, etc.), (2) information about the processor (e.g., weight, dimensions,

etc.), (3) information about the internal portion of the implant (e.g., weight, dimensions, etc.), and (4) reliability information. The fifth most beneficial category cannot be determined because three categories received the same number of references from parents. These categories are: (5a) information about MRI compatibility (e.g., removable magnet, strength of MRI that can be performed, etc.), (5b) information about water resistance, and (5c) information about the number of channels of each device. Fourteen parents (28%) skipped this question.

When asked to list the five categories that were most difficult to understand, parents reported the following: (1) maximum stimulation rate, (2) information about the electrodes and electrode array (e.g., number of electrodes, array configurations, etc.), (3) radio frequency (RF) carrier and data rate, (4) bone recess depth and elevation from bone, and (5) information about electrode drivers (e.g., maximum simultaneous electrode drivers). Twenty parents (40%) skipped this question.

When asked to report any categories not included on the provided chart that they thought would be beneficial during the decision-making process, parents reported the following suggested categories: cost information, more specific warranty information, number of device recipients/users worldwide, anatomical compatibility information, satisfaction rate, money spent on research and development, more specific reliability information, backwards compatibility information, available accessories, user testimonies, audiologist opinions, information about the ease and cost of replacing parts (including batteries), information about how the device works, historical problems and recalls, customer service response rates, available wearing options, speech perception information post-implantation, and information about the possibility of preserving natural hearing. Twenty-four parents (48%) skipped this question.

Parents were asked to offer one piece of advice regarding cochlear implant selection. A large variety of responses were reported. For a complete list of parent responses, see Table 1.

Discussion

The results of this study provided experiential information from parents about choosing a cochlear implant for their child, and information useful for creating a parent-friendly comparison chart of current cochlear implants. Parent responses about their personal experiences were helpful in understanding whether parents sought out or were given information regarding cochlear implants, from whom or from where parents received the information they were given, from whom or from where parents sought information about cochlear implants, in what format the information they used was presented, what was most important to parents when choosing a cochlear implant for their child, and how they ultimately decided which cochlear implant their child would receive. Parent responses about the provided comparison chart were helpful in developing a parent-friendly comparison chart, including whether parents think such a tool would be useful, which categories are important, and which categories need clearer explanations.

Nearly three-fourths of the original participants provided usable data for this study. This means that almost three-fourths of participants (parents of children implanted within the last eight years who are currently attending OPTION Schools) played an active role in deciding which cochlear implant their child received. Parents who did not have a choice in which cochlear implant their child received might have encountered any number of determining factors, including surgeon preference, insurance coverage, and anatomical compatibility of the internal device. Similarly, parents who had a choice between devices from two cochlear implant manufacturers instead of a choice among devices from all three cochlear implant manufacturers

might have been limited by device availability and popularity in their region of the country, surgeon preference, or appropriateness of the device for their child's hearing loss. Any of these factors can affect which device a child receives, regardless of what the parent is offered.

The survey contained five questions about the information parents used during their decision-making process. The responses to these questions indicated that parents relied most on audiologists for information about cochlear implants, particularly for the information they were given during the decision-making process. When searching for information, most parents sought information from as many places and people as possible, particularly cochlear implant manufacturers' websites. It is worth noting that none of the parents reported relying on information from friends or family who had limited knowledge of cochlear implants. This means that parents did not rely on the opinions of people who had formed those opinions without research or experience. More specifically, parents are attempting to make well-informed decisions regarding their child's cochlear implant and provides support for the need for a parent-friendly comparison tool. With this tool, parents can make more knowledgeable decisions based on information and research.

There was no one format of information that was more popular than the others. Information used by parents in this study was almost equally represented as electronic materials, printed materials, and information delivered as word of mouth. Each of these three formats were utilized about the same by parents who were researching cochlear implants. This further confirmed that parents seek a variety of materials to make informed decisions about selecting a cochlear implant for their child.

When choosing a cochlear implant for their child, parents most heavily considered technological aspects of the devices. Another considered factor was recommendations from

audiologists, physicians, and other health professionals. This further supported the finding that parents rely significantly on the information provided by audiologists. This also indicated that parents consider more than physical appearance alone and therefore need parent-friendly information regarding the technical aspects of the cochlear implants available. Parents also considered reliability of the devices over many other factors. This means parent-friendly information about device reliability should be available so parents can be informed about reliability before choosing a cochlear implant for their child.

More than three-fourths of parents reported that a cochlear implant comparison chart would have been helpful when deciding which device their child would receive. This supported the research aim to create such a tool for parents to use in the future. Two parents reported that they had tried to make comparison charts for themselves, and a few parents reported that the chart needed more parent-friendly language. Both of these claims confirmed the need for the proposed parent-friendly comparison chart created in tandem with this research project.

The survey questions that requested parents list beneficial and confusing categories found on the referenced comparison chart helped to determine the categories included on the parent-friendly comparison chart proposed within this project. Categories that were reported to be useful were included first, and parent-friendly explanations were added to provide more information to parents. Categories then were added based on the reportedly confusing categories, along with more parent-friendly explanations. Categories that parents suggested within the survey were considered, and some were added based on popularity and appropriateness, all with parent-friendly explanations. This comparison chart can be found at <http://www.cochlearimplantcomparison.com>.

Although interesting to read, the final survey question regarding parent advice was not utilized in the creation of the parent-friendly comparison chart. The variability and individuality of the responses did not lend itself to the creation of any new categories for the comparison chart, although the encouraging tone of the responses was carried over to the parent-friendly language of the comparison chart.

Limitations

There are a few factors that limit the application of results from this study. First, the small number of respondents and even smaller number of usable survey responses does not lend itself to “big picture” results. The reported results may be true for the surveyed population, but this is not to say they are true for all parents of children who utilize cochlear implants.

In addition, participants were recruited only from American OPTION Schools and their associated early intervention programs, which is a small population when compared to the total number of parents of children using cochlear implants across the country and around the world. There are children who use cochlear implants and currently attend schools within their local districts or who are home-schooled, children who use cochlear implants and attend schools for the deaf that are not OPTION Schools, and children who use cochlear implants and are being educated within self-contained classrooms or receiving services from an itinerant teacher of the deaf. By only recruiting parents from OPTION School programs, the number and variety of participants was limited.

Next, the predetermined cutoff date of implantation limited the potential participants to only those whose children had been implanted after the set date. This means parents of children who currently use cochlear implants but were implanted before January 1, 2006 were not eligible

to participate, though their opinions and experiences are still valid. For the purposes of the study, only parents of more recently implanted children were eligible in the hopes of keeping information as current and relevant as possible. This did, however, reduce the possible number of respondents.

Finally, the fact that participants were allowed to skip questions from the survey means survey responses were greatly limited. As noted in the results, some questions earned as few as twenty-six responses. With only fifty usable survey responses, this means nearly half of the respondents skipped that particular question. Therefore, the data from these low-response questions are even more limiting due to the smaller number of responses. The aforementioned factors indicate that the findings of the study are not generalizable to the entire population of parents whose children are receiving cochlear implants.

Future Research

This study was conducted on a very small scale. More extensive and more inclusive research must be done to gain insight into a wider array of parent experiences during the decision-making process.

Additionally, conducting research after distribution and publication of the comparison chart created for this project could be beneficial to validate the chart's usefulness among parents. This future research would help determine the reality of research-based claims of this independent study that the chart would be both comprehensive and parent-friendly. Should adjustments or further clarifications need to be made to the chart created from this project, further research regarding the chart's genuine use would help provide information for such development.

Similarly, research concerning the chart's use and how parents acquire and use information regarding cochlear implants may benefit cochlear implant manufacturers and audiologists alike. If they have a better understanding of what types of information parents choosing cochlear implants desire, they could provide this information to their patients. Such research may lend itself to changes in cochlear implant manufacturer marketing and audiology services.

Conclusion

This project had two aims: examine the information parents use during the cochlear implant decision-making process and create a tool that contains the desired information in a parent-friendly manner. The lack of a parent-friendly cochlear implant comparison chart, and the confirmed need for such a tool within the research conducted, led to the completion of a chart that meets this need. Survey responses helped to identify information and resources utilized by parents when choosing a cochlear implant for their child. The research also helped to determine what kinds of information needed to be included on the comparison chart.

The survey used to collect information for this project demonstrates from where information about cochlear implants comes and how parents obtain this information. This is important when considering the best way to distribute the parent-friendly comparison chart. In addition, the format of information used by parents helps in determining the feasibility of presenting the chart in more than one format in the future.

The parent-friendly cochlear implant comparison chart created in this project is intended to be used by parents who are trying to decide which cochlear implant will be best for their child. It may be shown to parents by audiologists or other professionals, or it may be accessed online

by parents who are seeking information about cochlear implants. In either case, it is expected that the parent-friendly comparison chart will help parents feel more informed and more confident when choosing a cochlear implant for their child.

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Figure 1: Manufacturer Representation Among Participants

Which manufacturer's implant does your child use?

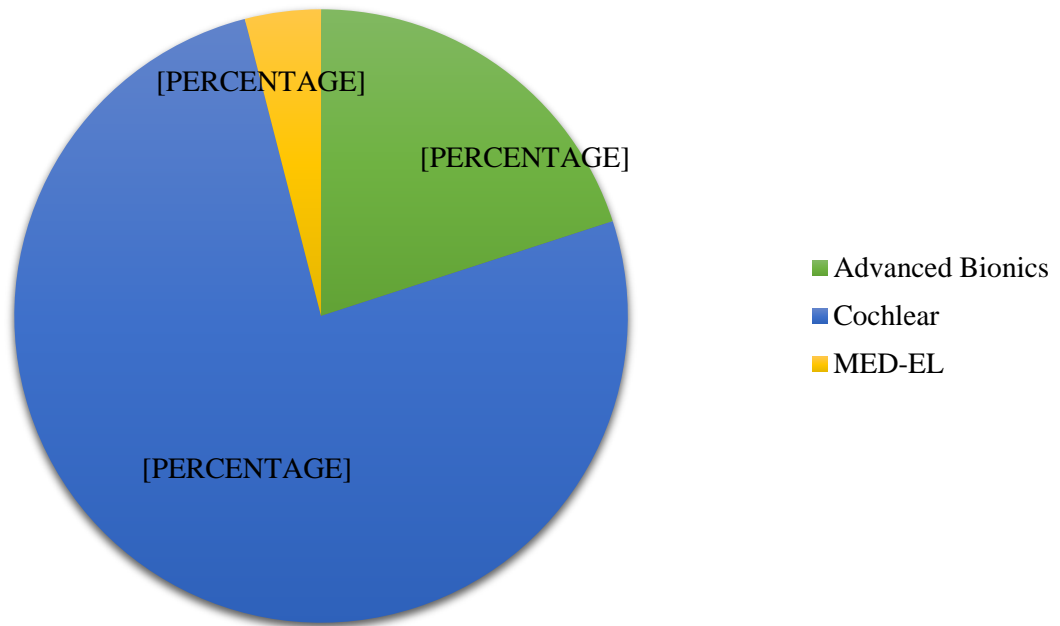


Figure 2: Parental Choice in Implantation

Did you have a choice in which cochlear implant your child received?

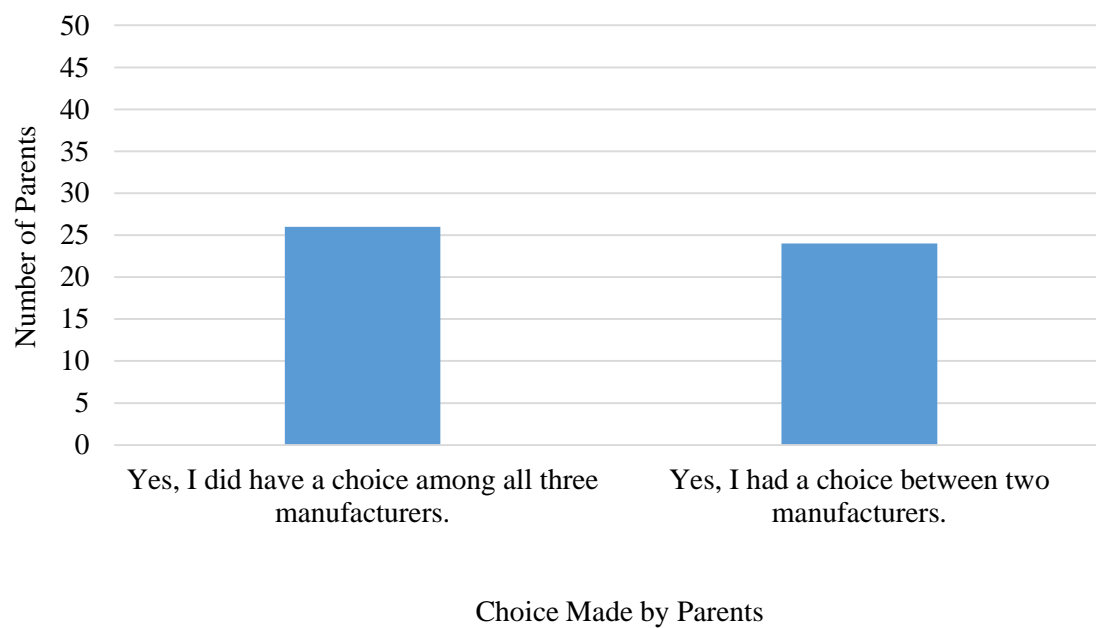


Figure 3: Primary Source of Information Regarding Cochlear Implantation

What would you consider your primary source of information about cochlear implants when choosing your child’s implant?

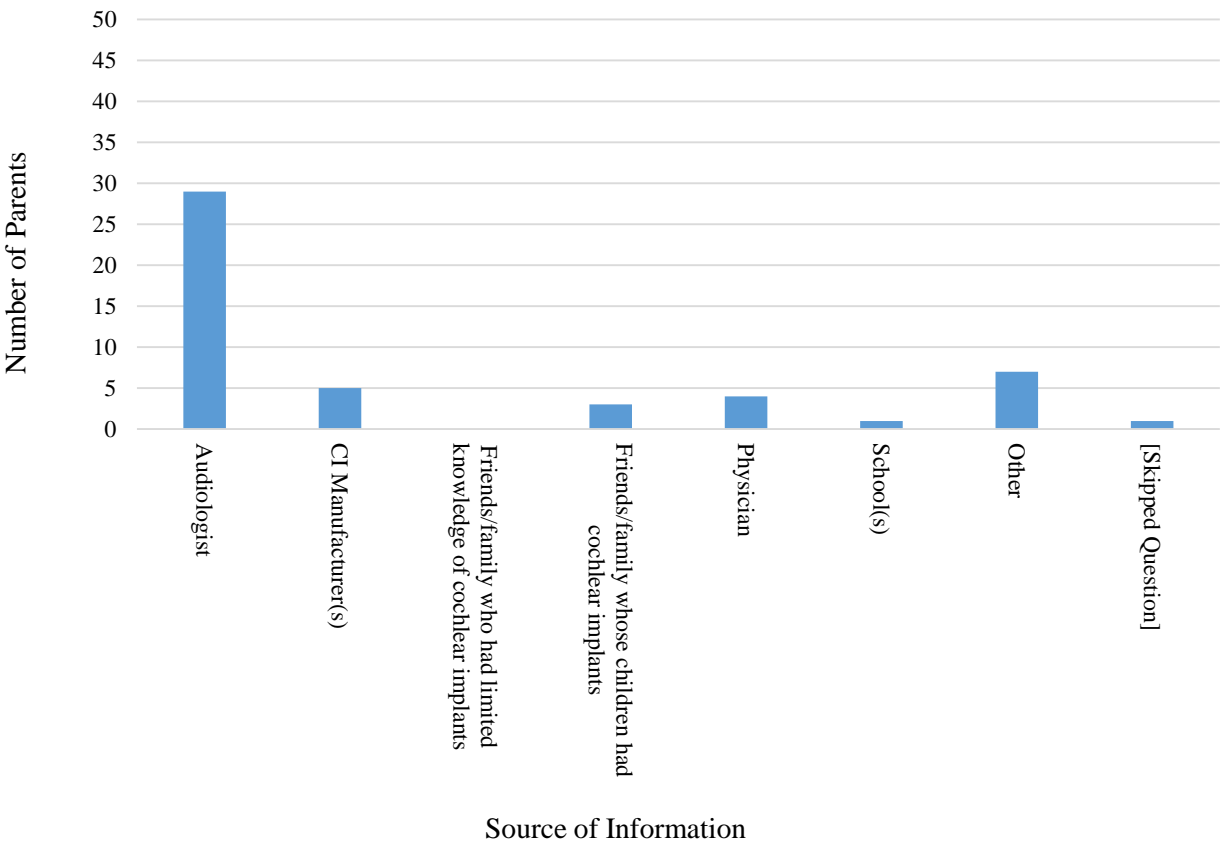
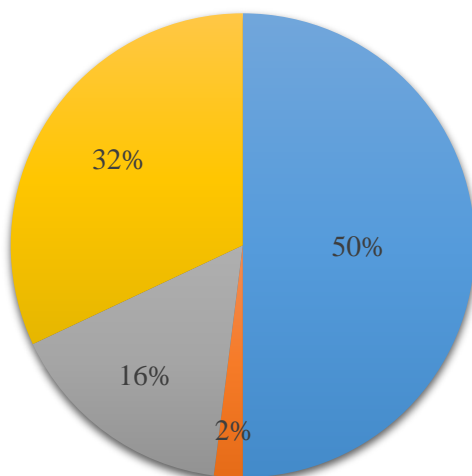


Figure 4: Acquisition of Information

Thinking about the information you used most, was it information you requested/found on your own, or was it given to you?



- I requested/looked for information from/in as many places as I could.
- I requested/looked for information from/in a few places.
- I was given all the information I used.
- I requested/looked for some information and was given some information.

Figure 5: From Whom/Where Information was Received

*From whom did you receive the information GIVEN (without asking) to you?
(Select all that apply.)*

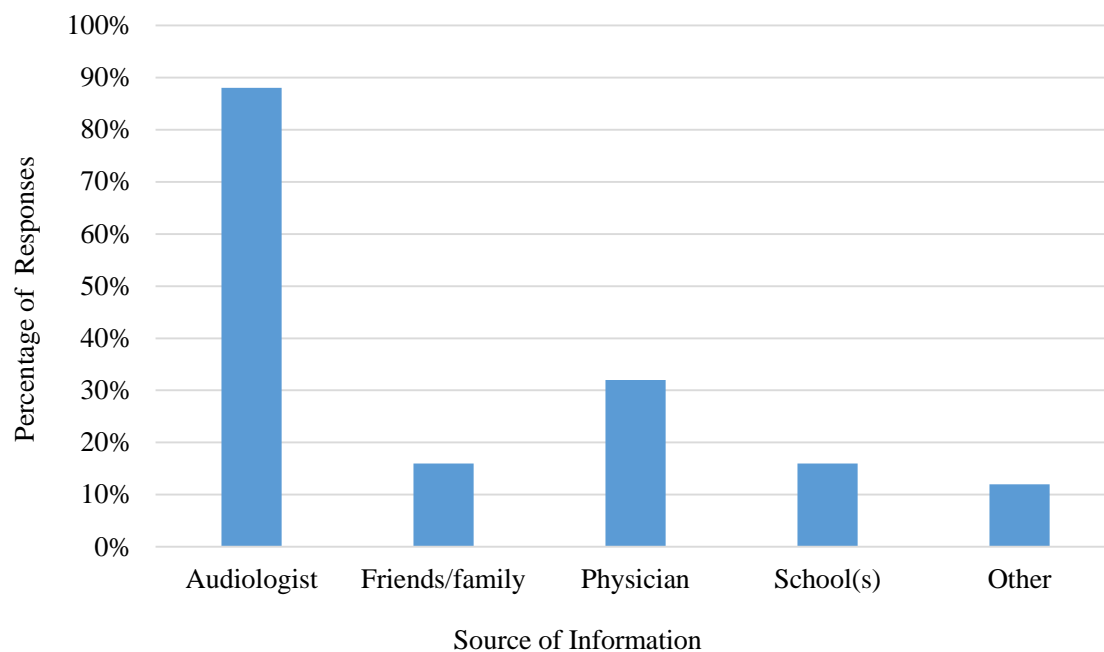


Figure 6: From Whom/Where Information was Requested

*From where did you receive the information you REQUESTED/FOUND?
(Select all that apply.)*

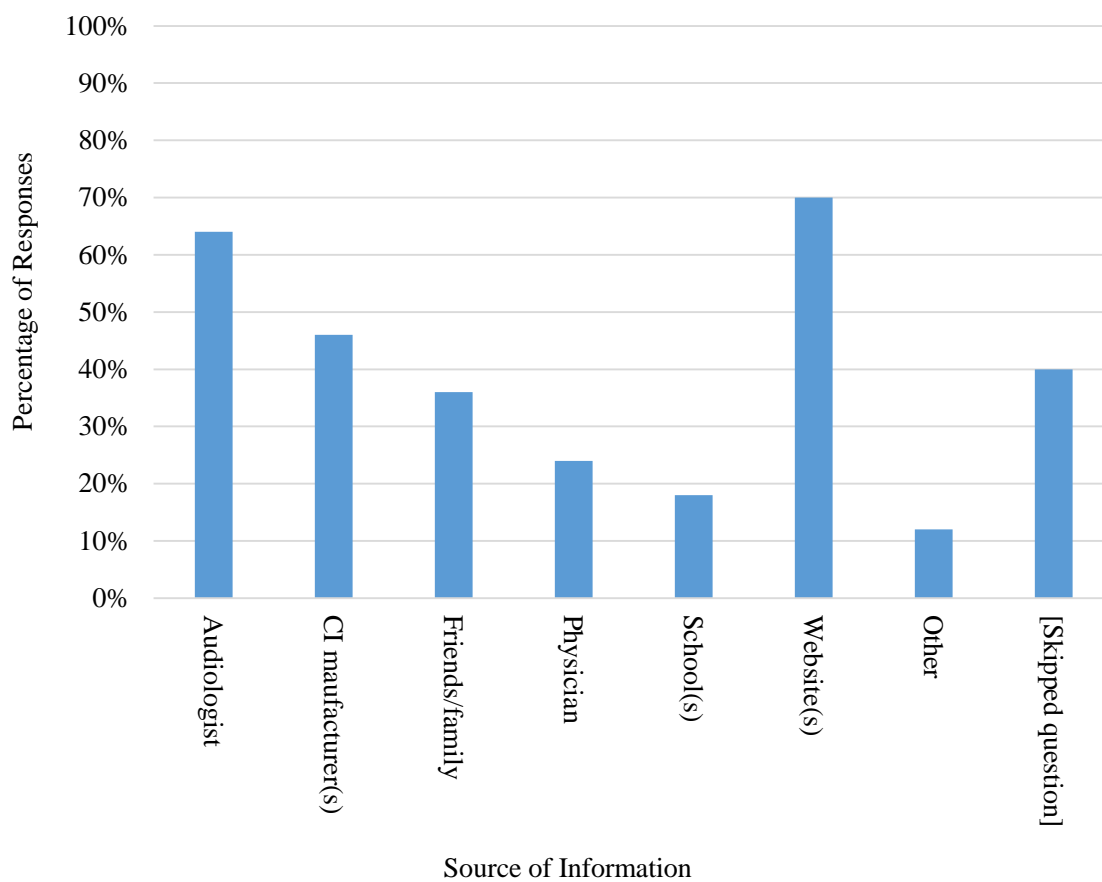


Figure 7: Format of Information

In what format did you receive the information you used?
(Select all that apply.)

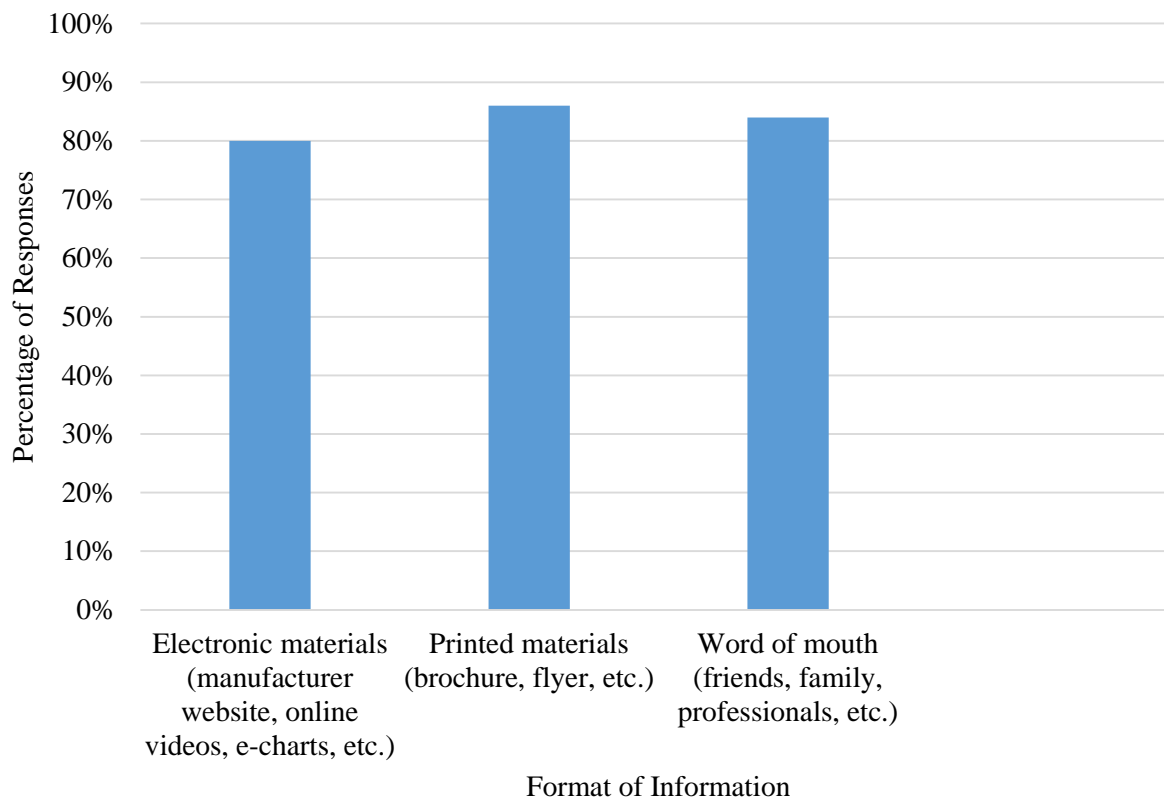


Figure 8: Most Important Consideration in Choice of Implant

What was most important to you when choosing which implant your child would use?

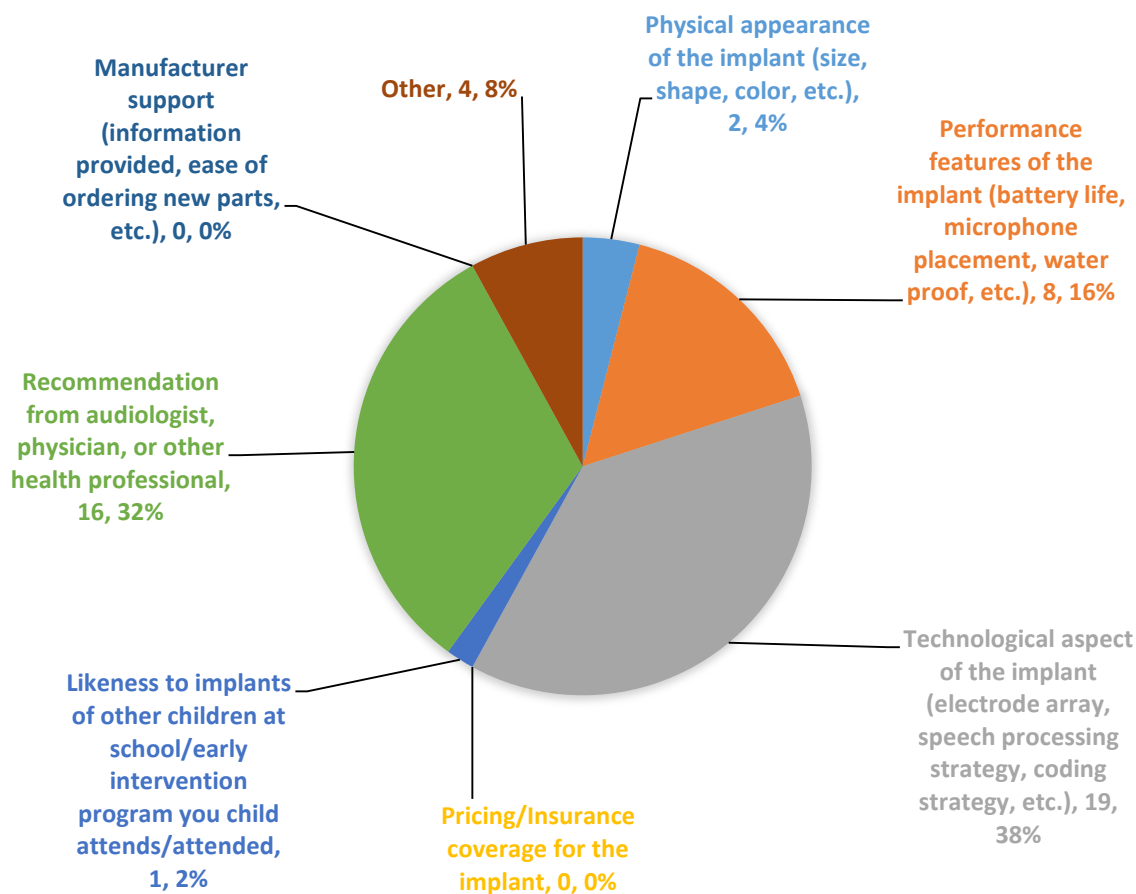


Table 1: Parental Advice Regarding Cochlear Implant Selection

If you could offer parents one piece of advice regarding cochlear implant selection, what would it be?

Respondent	Advice to Other Parents
1	Go with your provider's recommendation but still do some of your own research
2	Question everything. Getting a cochlear implant is a personal/familial decision. An implant may not work for every hearing loss, but it works for my son and our family. It changed our lives.
3	Trust your gut, and choose thinking that although an implant is forever, kids are rough and you need to pick something that allows them to act like kids.
4	Choose an implant made by a company that is continuing to make improvements and use current technologies.
5	Research and talk to parent of hearing impaired peers. Join [organization name] to seek out information there as well.
6	The devices are all excellent, but a great surgeon and solid therapy approach are very important...and the earlier you get the child access to sound, the better.
7	Make sure you do your research and get opinions from other parents/ kids who have the implant you want to go with.
8	Don't let anyone persuade you. Do your own research! The final decision is most likely your own.
9	Talk to other parents of children who have already been implanted if possible.
10	Research for yourself, don't pick one because it's the most familiar with friends or school.
11	Do lots of research and talking to other parents. Handle it, and see pics of it on others.
12	Don't look at the information for aesthetics alone, plan for your child to wear this device for many years and pick the technology you think will work the best.
13	Ease of FM use.
14	Educate yourself, and talk to users/parents from each company to get several first hand references.
15	Go with your gut and advice of audiologist.
16	Once you make your decision, don't look back. Children with all three brands of implant learn to speak and listen.
17	Gather as much information as possible, review it, talk to professionals about the info or any questions you have, decide what aspects of the implant are most important to you, and make a decision.
18	Think about how the company works with our insurance. The only disappointment I've had with [manufacturer] is that they don't work well with the insurance companies once the warranty is finished.
19	Consider the company that has better waterproofing technology. It is a huge part of our lives in the summer and I am unhappy with [manufacturer's] aqua accessory. It may have swayed us to choose an implant from [manufacturer] if it was available in 2008.
20	Do thorough research. Look at forward integration (and forward compatibility).

21	Do it as soon as possible! Make sure the implant is installed correctly via CT scan upon installation.
22	I believe that the parent should go with their gut after doing the research and also that it's not necessarily the product but the process – the appointments, therapy and wearing it all waking hours are the most important for success.
23	To do some research and get advice from someone you trust.
24	Don't listen to the manufacturer sales pitch. We almost went for the company that sent a person to our house. What a mistake that would have been. Listen to the community of your peers.
25	I think the 3 models all have pros and cons, and are fairly comparable. Parents should go with what feels right for their child, and not feel like one model is better than another.
26	With enough work, the outcomes can be the same no matter which device you pick, so don't agonize over it. Go with your gut and move on to the harder part: learning to use it!
27	Talk to people who have them, and find out their experiences with them and the companies. A chart like this can't tell you how customer service is, or what people feel about them.
28	Get a good audiologist. All the implants work fine. But audiology will make or break the success of the implant!
29	Talk to a lot of parents that live with them and have to take care of them with their children. That is the true test.
30	We felt more comfortable going with the most reliable thing we could at the time.
31	Do thorough research – decision lasts forever.
32	Obtain all information about each manufacturer's device and performance, safety, and daily use of said device.
33	Do your research. Don't just choose a device because "everyone else has it". The devices are different. They absolutely all work, and implanting your child is what really matters, but there are differences. You child will be using this device for the next 50 years, so do your research, and don't make your decision based on something silly, like how it looks. Looks change, your child won't be a baby forever. It is about choosing the best device that will provide the best hearing across your child's life.
34	Talking to other recipients and parents whose children have cochlear implants is very helpful. It's of course important to research the companies, but talking to people is also extremely beneficial in the decision process.
35	Really do your research before making a decision that works for your family.
36	Consult website and parent/patient advisors! [Specific person] with [manufacturer] was a great resource for us!
37	Knowing what I know now no matter your decision you have to do what's best for your child at that moment. I would have for sure done [manufacturer] if I would have known they were coming out with a waterproof processor. But at the time I was concerned about the implant we chose [being] the smallest so I went with that.
38	Talk to people with different brands of implants and get anecdotal feedback

	about their experience with each device.
39	Think long term: sports, bike helmets, water/sweat, durability, cell phone, attachments, and accessories. When my baby got implanted, I wasn't thinking about any of that long term stuff. These are some of the topics we have to deal with now that my child has grown.
40	Listen to your surgeon and audiologist, find other patients/parents to talk to. It is still an individual choice – do what is right for you or your family.

Appendix A: Parent Survey Questions

1. Please provide the date of your child's implantation, including the month and the year.
Note: If your child was sequentially implanted, please enter the date of the first implantation, and keep that first implantation in mind when answering the rest of the questions on the survey.
Month (1-12) [___] Year [____]
2. Which manufacturer's implant does your child use?
 - ☐ Advanced Bionics
 - ☐ Cochlear
 - ☐ MED-EL
3. Did you have a choice in which cochlear implant your child received?
 - ☐ Yes, I did have a choice among all three manufacturers.
 - ☐ Yes, I had a choice between two manufacturers.
 - ☐ No, I did not have a choice.
4. What would you consider your primary source of information about cochlear implants used when choosing your child's implant?
 - ☐ Audiologist
 - ☐ CI manufacturer(s)
 - ☐ Friends/family who had limited knowledge of cochlear implants
 - ☐ Friends/family whose children already had cochlear implants
 - ☐ Physician
 - ☐ School(s)
 - ☐ Other (please list)
5. Thinking about the information you used most, was it information you requested/found on your own, or was it given to you?
 - ☐ I requested/looked for information from/in as many places as I could.
 - ☐ I requested/looked for information from/in a few places.
 - ☐ I was given all the information I used.
 - ☐ I requested/looked for some information and was given some information.
6. From whom did you receive the information given (without asking) to you? (Select all that apply.)
 - ☐ Audiologist
 - ☐ Friends/family
 - ☐ Physician
 - ☐ School(s)
 - ☐ Other (please list)
7. From where did you receive the information you requested/found? (Select all that apply.)
 - ☐ Audiologist
 - ☐ CI manufacturer(s)

- Friends/family
 - Physician
 - School(s)
 - Website(s)
 - Other (please list)
8. In what format did you receive the information you used? (Select all that apply.)
- Electronic materials (manufacturer website, online videos, e-charts, etc.)
 - Printed materials (brochure, flyer, etc.)
 - Word of mouth (friends, family, professionals, etc.)
9. What was most important to you when choosing which implant your child would use?
- Physical appearance of the implant (size, shape, color, etc.)
 - Performance features of the implant (battery life, microphone placement, water proof, etc.)
 - Technological aspect of the implant (electrode array, speech processing strategy, coding strategy, etc.)
 - Pricing/Insurance coverage for the implant
 - Likeness to implants of other children at school/early intervention program your child attends/attended
 - Recommendation from audiologist, physician, or other health professional
 - Manufacturer support (information provided, ease of ordering new parts, etc.)
 - Other (please specify)
10. If possible, please briefly describe the “one thing” that helped you finally decide which implant your child received.

Please take a brief moment to look over the following chart before answering Questions 11-14.
 Chart: <http://dl.dropboxusercontent.com/u/84378947/CochlearImplantShoppingGuide.pdf>

11. Would a chart such as this have been helpful when deciding which implant your child would receive?
- Yes
 - No
 - Please explain why or why not. (Ex. “I did not need information this detailed.” or “It would have been beneficial to know about some of these smaller details/features.”)
12. Please list the five categories of the chart you think are most beneficial.
13. Please list up to five categories that were the most difficult to understand.
14. Are there any categories not listed on the chart that you think would be beneficial during the decision-making process?
15. If you could offer parents one piece of advice regarding cochlear implant selection, what would it be?